

Epilepsy in children and young people

Quality standard

Published: 28 February 2013

www.nice.org.uk/guidance/qs27

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This standard is based on CG137.

This standard should be read in conjunction with QS26, QS15, QS71 and QS101.

Introduction and overview

This quality standard covers the diagnosis and management of the epilepsies in children and young people (aged up to 18 years). For more information see the [scope for this quality standard](#).

Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. It is estimated that 34,000 children and young people in England with a diagnosis of epilepsy are currently receiving anti-epileptic drugs. There are more than 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy means that it can be difficult to diagnose accurately. [NICE's guideline on epilepsies: diagnosis and management](#) estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect. The [Joint Epilepsy Council](#) (2011) reported that up to 40% of children referred to tertiary epilepsy clinics do not have epilepsy. A diagnosis of epilepsy can have a wide-ranging impact on a child or young person's health and lifestyle. A key part of this quality standard is therefore focused on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are confirmed and reviewed as necessary.

For many children and young people diagnosed with epilepsy the seizures can be controlled through treatment with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activity. This quality standard therefore includes a focus on tailoring treatment to the individual circumstances and needs of children and young people with epilepsy so that they are offered the most suitable treatment.

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement. The quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following frameworks:

- [NHS Outcomes Framework 2013 to 14](#)
- [Public Health Outcomes Framework 2013 to 2016](#)

Overview

The quality standard for the epilepsies in children and young people specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole epilepsy care pathway. An integrated approach to the provision of services is fundamental to the delivery of high-quality care to children and young people with epilepsy, and the quality standard should be delivered by multidisciplinary teams through a local epilepsy clinical network.

The quality standard should be read in the context of national and local guidelines on training and competencies. All healthcare professionals involved in assessing, caring for and treating children and young people with epilepsy should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard.

List of quality statements

Statement 1 Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Statement 2 Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Statement 3 Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Statement 4 Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.

Statement 5 Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Statement 6 Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Statement 7 Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Statement 8 Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Statement 9 Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

In addition, quality standards that should also be considered when commissioning and providing a high-quality epilepsy service are listed in [related NICE quality standards](#).

Quality statement 1: Referral to a specialist

Quality statement

Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Rationale

Diagnosing epilepsy can be complex, and it has been estimated that misdiagnosis occurs in 5% to 30% of people. It is therefore crucial that specialists are involved early in diagnosing epilepsy and that they take great care to establish the correct diagnosis.

Quality measure

Structure

Evidence of local arrangements for children and young people presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Process

a) Proportion of children and young people presenting with a suspected seizure who are seen by a specialist in the diagnosis and management of the epilepsies.

Numerator – the number of people in the denominator who are seen by a specialist in the diagnosis and management of the epilepsies.

Denominator – the number of children and young people presenting with a suspected seizure.

b) Proportion of children and young people presenting with a suspected seizure who are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Numerator – the number of people in the denominator who are seen within 2 weeks of presentation.

Denominator – the number of children and young people presenting with a suspected seizure seen by a specialist in the diagnosis and management of the epilepsies.

Outcome

- a) Diagnosis of epilepsy that is subsequently found to be incorrect.
- b) Diagnosis of a condition that is subsequently found to be epilepsy.
- c) Number of children and young people with a recorded seizure type and/or syndrome.

What the quality statement means for each audience

Service providers ensure systems are in place for children and young people presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Healthcare professionals ensure that children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Commissioners ensure they commission services for children and young people presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Children and young people who have a suspected seizure are seen by a doctor with training and expertise in diagnosing and treating epilepsy within 2 weeks.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012), recommendations 1.4.6 (key priority for implementation), 1.4.1 and 1.4.2

Data source

Structure

Local data collection.

Process

a) and b) Local data collection.

Outcome

a) Organisations can collect data on the percentage of children where there is evidence that a diagnosis of epilepsy (two or more epileptic seizures) was made and then later withdrawn at any time during 12 months after first paediatric assessment using the [Epilepsy12 national audit \(Royal College of Paediatrics and Child Health\)](#), section 3.10.

b) Local data collection.

c) Organisations can collect data on the diagnosis made by the paediatric team by the end of the 12 months after first paediatric assessment using the [Epilepsy12 national audit \(Royal College of Paediatrics and Child Health\)](#), section 3.9.

Definitions

A suspected epileptic seizure is a reported acute episode of altered functioning, presumed to be the direct result of a change in electrical activity in the brain, the nature of which raises concerns that a seizure has occurred.

A specialist in the diagnosis and management of the epilepsies in children and young people is a paediatrician with training and expertise in epilepsy who has, for example, completed the [Royal College of Paediatrics and Child Health specialist training module on epilepsy](#) or worked for a minimum of 6 months in a tertiary centre for neurology in children and attended appropriate paediatric epilepsy training courses. The care of the specialist's patients with epilepsy should be part of an ongoing peer review process related to epilepsy care.

Quality statement 2: Investigations

Quality statement

Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Rationale

The period between the suspected seizure occurring and diagnosis can be a particularly anxious time for patients and families and it is therefore important that investigations are conducted in a timely manner. The earlier a correct diagnosis of epilepsy is made, the sooner tailored therapy can be initiated. Delays caused by a lack of available diagnostic equipment can lead to distress and impact negatively on the everyday lives of patients.

Quality measure

Structure

Evidence of local arrangements for children and young people having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

Process

Proportion of children and young people having initial investigations for epilepsy who undergo the tests within 4 weeks of them being requested.

Numerator – the number of people in the denominator who undergo the tests within 4 weeks of the request.

Denominator – the number of children and young people having initial investigations for epilepsy.

Outcome

Patient or parent/carer satisfaction with the length of time between tests being arranged and the tests being performed.

What the quality statement means for each audience

Service providers ensure systems are in place for children and young people having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

Healthcare professionals ensure that children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Commissioners ensure they commission services for children and young people having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

Children and young people having their first tests for epilepsy have the tests within 4 weeks of them being requested by the doctor.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012), recommendations 1.6.3 and 1.6.22

Data source

Structure

Local data collection.

Process

Local data collection.

Outcome

Local data collection.

Definitions

Initial investigations for epilepsy include electroencephalogram (EEG) and magnetic resonance imaging, as appropriate.

Tests such as long-term video or ambulatory EEG, which might be used in the assessment of

children and young people in whom there are difficulties with diagnosis after clinical assessment and standard EEG, might not be possible within this timeframe.

Test results should be interpreted by practitioners who have the necessary competencies.

Information should be provided to children and young people, and their families and/or carers as appropriate, on the reasons for the tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them.

Equality and diversity considerations

Very young children, or children and young people with learning disabilities or challenging behaviour, might need particular care and attention to help them tolerate investigations. The same services and investigations should be offered to children and young people with learning disabilities as are offered to the general population.

Quality statement 3: Magnetic resonance imaging

Quality statement

Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Rationale

Magnetic resonance imaging (MRI) is shown by evidence to be the most sensitive and specific neuroimaging option in terms of identifying structural abnormalities in the brain, but access to MRI scanning and reporting facilities varies across the country.

Quality measure

Structure

a) Evidence of local arrangements for children and young people who meet the criteria for neuroimaging for epilepsy to have MRI.

b) Evidence of local arrangements for children and young people with learning disabilities who meet the criteria for neuroimaging for epilepsy to have MRI.

Process

Proportion of children and young people who meet the criteria for neuroimaging for epilepsy who have MRI.

Numerator – the number of people in the denominator who have MRI.

Denominator – the number of children and young people who meet the criteria for neuroimaging for epilepsy.

What the quality statement means for each audience

Service providers ensure systems are in place for children and young people who meet the criteria for neuroimaging for epilepsy to have MRI.

Healthcare professionals ensure that children and young people who meet the criteria for neuroimaging for epilepsy have MRI.

Commissioners ensure they commission services for children and young people who meet the criteria for neuroimaging for epilepsy to have MRI.

Children and young people who are having neuroimaging (taking pictures of the brain) for epilepsy have magnetic resonance imaging (a type of neuroimaging that uses magnetic fields to produce a picture of the brain; often shortened to MRI).

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012), recommendation 1.6.20

Data source

Structure

a) and b) Local data collection.

Process

Local data collection. Organisations can collect data on the percentage of children with defined indications for MRI who had MRI within 1 year using the Epilepsy 12 national audit (Royal College of Paediatrics and Child Health), section 9a.

Definitions

Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. People diagnosed with idiopathic generalised epilepsy or benign epilepsy with centrotemporal spikes are unlikely to have any aetiologically relevant structural abnormalities and should not therefore undergo neuroimaging.

The criteria for MRI in children and young people are newly diagnosed epilepsy in a child aged

under 2 years, epilepsy with focal onset (unless there is evidence of benign epilepsy with centrotemporal spikes) and failure of first-line medication.

In acute situations computed tomography may be used to determine whether a seizure has been caused by an acute neurological lesion or illness. Computed tomography should be used for children and young people for whom a general anaesthetic or sedation would be needed for MRI but would not be needed for computed tomography.

Equality and diversity considerations

The same services, investigations and therapies should be offered to children and young people with learning disabilities or challenging behaviour as are offered to the general population.

Children and young people with learning disabilities or challenging behaviour might need particular care and attention to help them tolerate investigations. Reasonable adjustments, such as offering open-bed scanners, sedation or general anaesthesia, should be made if necessary to ensure all children and young people who need MRI have access to it.

Good communication and a supportive environment are important in helping children to undergo investigative tests. Play therapy may also have a role in supporting children having neuroimaging for epilepsy.

Quality statement 4: Epilepsy care plan

Quality statement

Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.

Rationale

There are a number of potential lifestyle, health and wellbeing implications directly related to epilepsy. A care plan is an important tool in ensuring that all aspects of a person's life that could be affected by their epilepsy syndrome and the treatment they are receiving are considered and addressed.

Quality measure

Structure

Evidence of local arrangements for children and young people with epilepsy to have an agreed and comprehensive written epilepsy care plan.

Process

a) Proportion of children and young people with epilepsy who have an agreed and comprehensive written epilepsy care plan.

Numerator – the number of people in the denominator who have an agreed and comprehensive written epilepsy care plan.

Denominator – the number of children and young people with epilepsy.

b) Proportion of children and young people with an epilepsy care plan, or their parents or carers who feel they have been involved in developing and agreeing their plan.

Numerator – the number of people in the denominator, or their parents or carers, who feel they have been involved in developing and agreeing their plan.

Denominator – the number of children and young people with an epilepsy care plan.

Outcome

- a) Patient or parent/carer satisfaction with involvement in the epilepsy care planning process.
- b) Parent/carer satisfaction with involvement in the epilepsy care planning process.

What the quality statement means for each audience

Service providers ensure that systems are in place for children and young people with epilepsy to have an agreed and comprehensive written epilepsy care plan.

Healthcare professionals ensure that children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.

Commissioners ensure they commission services for children and young people with epilepsy to have an agreed and comprehensive written epilepsy care plan.

Children and young people with epilepsy or carers have a written epilepsy care plan that includes details about treatment and any preferences and lifestyle issues, and is agreed between them (and their parents or carers if appropriate) and their healthcare team.

Source guidance

[Epilepsies: diagnosis and management. NICE guideline CG137 \(2012\), recommendations 1.3.1 and 1.8.2](#)

Data source

Structure

Local data collection.

Process

- a) and b) Local data collection.

Outcome

a) and b) Local data collection.

Definitions

The comprehensive epilepsy care plan should be a written record of the decisions made about the child's or young person's past, present and future care.

It should be discussed and agreed between the child or young person with epilepsy, their parents and/or carers and their primary and secondary health and social care professionals. A local template or checklist should be developed to ensure consistency in the content of each epilepsy care plan based on [NICE's guideline on epilepsies](#), recommendation 1.3.1. The plan should be reviewed at least annually.

The care plan should include any issues relating to the following topics (as listed in [NICE's guideline on epilepsies](#), recommendation 1.3.1):

- epilepsy in general
- the child's or young person's specific epilepsy syndrome
- diagnosis and treatment options
- medication and side effects
- seizure type(s), triggers and seizure control
- management and self-care
- risk management
- first aid, safety and injury prevention at home and at school or work
- psychological issues
- social security benefits and social services
- insurance issues
- education and healthcare at school

- importance of disclosing epilepsy in college or at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted)
- road safety and driving
- prognosis
- sudden unexpected death in epilepsy (SUDEP)
- status epilepticus
- lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation)
- family planning and pregnancy
- voluntary organisations, such as support groups and charitable organisations, and how to contact them.

Equality and diversity considerations

Consideration should be given to the capacity of someone with epilepsy to be involved in agreeing their epilepsy care plan. Best interest decision making, in accordance with the Mental Capacity Act, should be adhered to.

Quality statement 5: Epilepsy specialist nurse

Quality statement

Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Rationale

Epilepsy specialist nurses play a key role in supporting continuity of care between settings for people with epilepsy. There is some evidence that epilepsy specialist nurses improve clinically important outcomes such as knowledge, anxiety and depression for people with epilepsy in secondary and tertiary care.

Quality measure

Structure

Evidence of local arrangements for children and young people with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Process

a) Proportion of children and young people with epilepsy who have seen a named epilepsy specialist nurse at diagnosis.

Numerator – the number of people in the denominator who have seen an epilepsy specialist nurse at diagnosis.

Denominator – the number of children and young people with epilepsy.

b) Proportion of children and young people with epilepsy who have seen an epilepsy specialist nurse at their review.

Numerator – the number of people in the denominator who have seen an epilepsy specialist nurse at their review.

Denominator – the number of children and young people with epilepsy.

c) Proportion of children and young people with epilepsy who have the contact details of a named epilepsy specialist nurse.

Numerator – the number of children and young people in the denominator who have the contact details of a named epilepsy specialist nurse.

Denominator – the number of children and young people with epilepsy.

Outcome

Patient or parent/carers satisfaction with access to epilepsy specialist nursing.

What the quality statement means for each audience

Service providers ensure that systems are in place for children and young people with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Health and social care professionals ensure that children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Commissioners ensure they commission services for children and young people with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Children and young people with epilepsy see an epilepsy specialist nurse (a nurse who has training and experience in caring for people with epilepsy) who they or their parent/carers can contact between scheduled reviews.

Source guidance

[Epilepsies: diagnosis and management. NICE guideline CG137](#) (2012), recommendation 1.8.3

Data source

Structure

Local data collection.

Process

a), b) and c) Local data collection. Organisations can collect data on the percentage of children with evidence of input by, or referral to, an epilepsy specialist nurse within 1 year using the [Epilepsy12 national audit](#) (Royal College of Paediatrics and Child Health), section 2.

Outcome

Local data collection.

Definitions

The role of the epilepsy specialist nurse is described in [NICE's guideline on epilepsies](#), recommendation 1.8.3 as: to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and wellbeing.

Epilepsy specialist nursing may be provided in a number of different teams, for example the learning disabilities team.

At diagnosis in this context means within 3 months of the epilepsy diagnosis being confirmed.

Quality statement 6: Prolonged or repeated seizures

Quality statement

Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Rationale

An emergency care plan is an important tool in improving the quality of emergency care in the community. It ensures that previous incidents and the agreed treatment strategies are taken into account by healthcare professionals. It also provides guidance for family members or carers who may need to administer emergency treatment. The timely and appropriate management of a prolonged or repeated seizure may significantly reduce the risk of mortality and morbidity (long-term complications) known to be associated with prolonged or repeated seizures.

Quality measure

Structure

Evidence of local arrangements for children and young people with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

Process

Proportion of children and young people with a history of prolonged or repeated seizures who have an agreed written emergency care plan.

Numerator – the number of people in the denominator who have an agreed written emergency care plan.

Denominator – the number of children and young people with a history of prolonged or repeated seizures.

Outcome

- a) Accident and emergency attendances for prolonged or repeated seizures.
- b) Hospital admissions for prolonged or repeated seizures.
- c) Patient or parent/carer satisfaction with emergency care for prolonged or repeated seizures.

What the quality statement means for each audience

Service providers ensure systems are in place for children and young people with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

Healthcare professionals ensure that children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Commissioners ensure they commission services for children and young people with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

Children and young people who have had a prolonged seizure (a seizure that lasted 5 minutes or longer) or repeated seizures have a written emergency care plan agreed between them, their parents or carers and their healthcare team that sets out how they should be cared for if they have prolonged or repeated seizures again.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012), recommendation 1.14.1.4

Data source

Structure

Local data collection.

Process

Local data collection.

Outcome

a) NHS Digital's Hospital episode statistics contain the data necessary for the monitoring of accident and emergency attendances.

b) and c) Local data collection.

Definitions

An agreed written emergency care plan should describe what happens in the event of a prolonged or repeated seizure, including pharmacological treatment that should be given and actions to take, who to contact and when. It should be agreed between the child or young person with epilepsy, their family and/or carers if appropriate and their primary and secondary healthcare professionals. Family members and/or carers of children and young people with epilepsy will need training to initiate treatment at home or in the community when necessary. The plan should be reviewed at least annually.

Prolonged seizures are seizures that last 5 minutes or more.

Repeated seizures are seizures that occur 3 times or more within 1 hour.

Any child or young person with epilepsy who has experienced a prolonged or repeated seizure is considered to have a history of prolonged or repeated seizures.

Quality statement 7: Referral to tertiary care

Quality statement

Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Rationale

Tertiary referrals can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on drugs, surgery, epilepsy combined with other complicated medical conditions or psychological problems. Timely and appropriate access to tertiary services remains variable across the country.

Quality measure

Structure

Evidence of local arrangements for children and young people who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

Process

Proportion of children and young people who meet the criteria for referral to a tertiary care specialist who are seen within 4 weeks of referral.

Numerator – the number of people in the denominator who are seen within 4 weeks of referral.

Denominator – the number of children and young people who meet the criteria for referral to a tertiary care specialist.

Outcome

Patient or parent/carers satisfaction with referral to tertiary care specialist.

What the quality statement means for each audience

Service providers ensure systems are in place for children and young people who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

Healthcare professionals ensure that children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Commissioners ensure they commission services for children and young people who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

Children and young people who meet the criteria for referral to a tertiary care specialist (someone who works as part of a specialist centre with a team of healthcare professionals experienced in assessing epilepsy that is hard to treat or complicated) are seen within 4 weeks of referral.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012), recommendation 1.10.2

Data source

Structure

Local data collection.

Process

Local data collection.

Outcome

Local data collection.

Definitions

NICE's guideline on epilepsies recommends that referral to tertiary services should be considered when 1 or more of the following criteria are present:

- The epilepsy is not controlled with medication within 2 years of onset.

- Management is unsuccessful after 2 drugs.
- The child is under 2 years of age.
- The child or young person experiences, or is at risk of, unacceptable side effects from medication.
- There is a unilateral structural lesion.
- There is psychological or psychiatric comorbidity.
- There is diagnostic doubt as to the nature of the seizures or the seizure syndrome.

A tertiary care specialist in epilepsy is an adult or paediatric neurologist who devotes the majority of their working time to epilepsy, is working in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review.

Quality statement 8: Review

Quality statement

Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Rationale

Reviews are important in ensuring that ongoing interventions are effective in meeting the needs of children and young people and to identify any changes in how their epilepsy is being controlled. They also ensure that epilepsy care plans remain relevant and up-to-date.

Quality measure

Structure

Evidence of local arrangements for children and young people with epilepsy to have a structured review with a paediatric epilepsy specialist at least annually.

Process

Proportion of children and young people with epilepsy whose most recent structured review with a paediatric epilepsy specialist was no later than 1 year (or individually agreed interval) after their previous review.

Numerator – the number of people in the denominator whose most recent structured review with a paediatric epilepsy specialist was no later than 1 year (or individually agreed interval) after their previous review.

Denominator – the number of children and young people with epilepsy.

Outcome

- a) Patient or parent/carer satisfaction with review content.
- b) Patient or parent/carer satisfaction with the frequency of the review.

What the quality statement means for each audience

Service providers ensure systems are in place for children and young people with epilepsy to have a structured review with a paediatric epilepsy specialist at least annually.

Health and social care professionals ensure that children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Commissioners ensure they commission services for children and young people with epilepsy to have a structured review with a paediatric epilepsy specialist at least annually.

Children and young people with epilepsy meet with a paediatric epilepsy specialist (a doctor who treats and cares for children and who has also had special training in diagnosing and treating epilepsy) at least once every year to talk about their treatment and any other problems they might be having with their epilepsy.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012), recommendations 1.20.3 and 1.20.5

Data source

Structure

Local data collection.

Process

Local data collection.

Outcome

a) and b) Local data collection.

Definitions

A structured review should cover all aspects of the child's or young person's epilepsy care plan. The physical, psychological and social needs of children and young people with epilepsy should always

be considered by healthcare professionals. Attention should be paid to their relationships with family and friends, and at school.

For children and young people, the maximum interval between reviews should be 1 year, but the frequency of reviews should be determined by the child's or young person's epilepsy, their wishes and the wishes of their family and/or carers. The interval between reviews should be agreed between the child or young person, their family and/or carers as appropriate, and the paediatric epilepsy specialist, but is likely to be between 3 and 12 months.

A paediatric epilepsy specialist in the management of the epilepsies is a paediatrician with training and expertise in epilepsy who has, for example, completed the [Royal College of Paediatrics and Child Health specialist training module on epilepsy](#) or worked for a minimum of 6 months in a tertiary centre for epilepsy in children and attended appropriate paediatric epilepsy training courses. The care of the specialist's patients with epilepsy should be part of an ongoing peer review process related to epilepsy care.

Quality statement 9: Transition from children's to adult services

Quality statement

Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Rationale

The need for continuity of care during transition from paediatric to adult services is particularly important for young people managing the physical and mental transition from adolescence to adulthood. Good management of this transition period by healthcare professionals is vital to develop and maintain the self-esteem and confidence of the adolescent with epilepsy. It also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood.

Quality measure

Structure

Evidence of local arrangements for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Process

Proportion of young people with epilepsy who are being discharged from paediatric epilepsy services who had an agreed transition period between paediatric and adult services.

Numerator – the number of people in the denominator who had an agreed transition period between paediatric and adult services.

Denominator – the number of young people with epilepsy who are no longer being cared for by paediatric services.

Outcome

Young people's experience of transition to adult services.

What the quality statement means for each audience

Service providers ensure systems are in place for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Healthcare professionals ensure young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Commissioners ensure they commission services for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Young people with epilepsy who are changing over from children's to adult health care services have a period of time when they are supported by both children's and adult services so that the changeover is handled smoothly.

Source guidance

[Epilepsies: diagnosis and management. NICE guideline CG137 \(2012\), recommendation 1.17.5](#)

Data source

Structure

Local data collection.

Process

a) and b) Local data collection.

Outcome

Local data collection.

Definitions

The purpose of the joint review is to optimise care and treatment for young people with epilepsy and help their move into adult services.

The period of transition should be a joint clinical action between paediatric and adult services, with at least 1 meeting at a joint consultation and a clear action plan for conducting a review after the young person has transferred into adult services.

Equality and diversity considerations

People with learning disabilities might need a longer transition period to accommodate the additional complexity of their clinical and psychological needs. In addition, people with learning disabilities might remain in paediatric services for longer than those without learning disabilities, depending on their personal preferences, ability to manage their own condition and clinical needs.

Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in the evidence sources section.

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of healthcare. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. As quality standards are intended to drive up the quality of care, achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, we recognise that this may not always be appropriate in practice taking account of patient safety, patient choice and clinical judgement, and therefore desired levels of achievement should be defined locally.

For further information, including guidance on using quality measures, see [how to use quality standards](#).

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and [equality assessments for this quality standard](#) are published on the NICE website.

Good communication between health and social care professionals and children and young people with epilepsy (or their parents/carers) is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Children and young people with epilepsy should have access to an interpreter or advocate if needed.

Development sources

Evidence sources

The document below contains clinical guideline recommendations or other recommendations that were used by the Topic Expert Group to develop the quality standard statements and measures.

[Epilepsies: diagnosis and management. NICE guideline CG137](#) (2012; NICE accredited)

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- Royal College of Physicians and Association of British Neurologists. Local adult neurology services for the next decade (2011)
- [Department of Health. Transition: getting it right for young people](#) (2016)
- [Department of Health. The National Service Framework for long term conditions](#) (2005)
- [Department of Health. National service framework for children, young people and maternity services](#) (2004)
- [Department of Health. Improving services for people with epilepsy: Department of Health action plan in response to the National Clinical Audit of epilepsy-related death](#) (2003)

Definitions, and data sources for the quality measures

References included in the definitions and data sources sections:

- [Royal College of Paediatrics and Child Health. Epilepsy12 national audit](#)
- [NHS Digital. Hospital Episode Statistics](#)

Related NICE quality standards

- [Transition from children's to adult services. NICE quality standard 140 \(2016\)](#)
- [Medicines optimisation. NICE quality standard 120 \(2016\)](#)
- [Epilepsy in adults. NICE quality standard 26 \(2013\)](#)
- [Patient experience in adult NHS services. NICE quality standard 15 \(2012\)](#)

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About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

Information about the topic experts is available from the [webpage for this quality standard](#).

This quality standard has been included in the [NICE Pathway on epilepsy](#), which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

ISBN: 978-1-4731-0049-7

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Royal College of Paediatrics and Child Health](#)
- [Association of British Neurologists \(ABN\)](#)
- [Epilepsy Action](#)
- [Epilepsy Society](#)
- [Royal College of General Practitioners \(RCGP\)](#)